February 5, 2014

Iowa Prevention of Disabilities Policy Council

February 5, 2014

100 Hawkins Drive
277 Center for Disabilities
and Development
Iowa City, Iowa 52242

Michael Marshall
Secretary of the Senate
State Capitol Building

Carmine Boal
Chief Clerk of the House
State Capitol Building

Re: 2013 Prevention of Disability Policy Summit Report

Please find enclosed the report from the Prevention of Disability Policy Summit held December 5, 2013. The members of the Prevention of Disability Policy Council appreciate the opportunity to share this information with you. We look forward to working with you in the future to address the important issues identified by the Summit participants.

If you have any questions regarding the report please contact:

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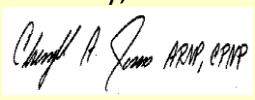
Sincerely,



Cheryll Jones

CC:

Jack Hatch, Chair
Mark Costello, Vice Chair
Mark Segebart, Ranking Member
David Heaton, Chair
Amanda Ragan, Vice Chair
Lisa Heddens, Ranking Member
Legislative Services Agency
Aaron Todd, Senate Majority Staff
Josh Bronsink, Senate Minority Staff
Carrie Malone, House Majority Staff
Zeke Furlong, House Minority Staff

2013 Disability Policy Summit:
Preventing Disabilities & Ensuring Access to Care

Final Summit Report and Recommendations

February 5, 2014

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EXECUTIVE SUMMARY

Background

In 2013, the Iowa General Assembly authorized and funded the Iowa Prevention of Disabilities Policy Council (Council) to conduct a summit to develop a state agenda and provide policy recommendations regarding the prevention of disabilities and their secondary conditions. The daylong **2013 Disability Policy Summit: Preventing Disabilities & Ensuring Access to Care** took place on December 5, 2013 at the Courtyard by Marriott in Ankeny, Iowa.

In choosing the topics to be covered during the Summit, the Council determined that those topics chosen should address prevention across the life span and at all three levels, i.e., primary, secondary and tertiary prevention. The Council gave preference to topics for which there were significant unmet needs and for which an investment in prevention would yield substantial results. After consulting with the Summit's 15 co-sponsors and other disability partners, the Council selected the following three topics to be addressed at the Summit:

- **Building inclusive, accessible communities that foster independence and access to healthcare**
- **Supporting children and families to optimize child health and development**
- **Preventing injuries that result in disability**

The Summit drew around 130 participants who developed 27 recommendations for state policy makers to consider. The recommendations developed would affect both policy and programs. Some of the recommendations would require legislative action and some can be handled by other public or private agency policy makers. Several of the recommendations require further refinement in order to move forward as policy and/or program options. After consideration of the Summit recommendations at its January 2014 meeting, the Council has selected the following priority recommendations to bring to the General Assembly at this time.

Priority Recommendations

<u>Building Accessible Iowa Communities that are Inclusive of Everyone</u>

Just because an individual has a condition or impairment such as cerebral palsy, limb loss, visual impairment, or heart disease does not necessarily mean that individual has a disability. Disability relates to an individual's ability to function and perform major life activities. For many individuals with such impairments, they will not become disabled if they can fully access community environments, activities, and services. Although the American with Disabilities Act (ADA) has brought about many improvements in access, there is much more to do.

Recommendation: Develop a new ACCESS Iowa initiative to promote greater participation by people with disabilities in Iowa communities. The initiative would address both:

- Access to state and local governmental environments, activities and services, and

- Ways to improve access to all community environments, activities and services.

Increasing Access to Health Care for People with Injuries, Disabilities and Chronic Health Conditions

Children and adults with disabilities are at risk of developing secondary health conditions that can add to their level of disability and increase their level of dependence on specialized services. People with disabilities face numerous barriers in accessing health care services including cost, transportation, accessibility of health care environments and equipment, availability of services (particularly specialty services), health care provider communication skills and training, and limited provider time during visits due to current reimbursement methodologies. Assuring access to needed health care for people with disabilities will prevent many secondary conditions that are costly for the individual and the state.

Recommendation: Provide consistent insurance coverage for telehealth services by legislatively requiring both Medicaid and private insurance companies to cover telehealth services.

Improving Early Identification and Intervention

Children are indeed our future. Research has shown the importance of the environment on brain development in early childhood and has linked adverse childhood experiences (ACEs) with poor adult health status. Early identification and intervention for factors that place children at risk for disability and poor health outcomes in adulthood are critical pieces of a state agenda to prevent disabilities.

Recommendation: Provide access for all Iowa children to early identification and early intervention services that can prevent or reduce serious disabilities.

- Implement the 1st Five Healthy Mental Development Initiative for children ages 0-5 in all Iowa counties; and
- Invest in a coordinated system of childhood services that provides individualized developmental and behavioral interventions for children with disabilities and those at high risk for disabilities.

Improving Disability Services for Iowans with Disabilities

Iowa is in the midst of reforming its system of services for people with disabilities. It is important that the new system is adequately funded, that individuals do not wait up to 2 years to access needed services, and that programs are designed to provide equity, support the state's preference for community-based services and allow flexibility to meet the needs of each individual. Providing adequate and timely services that meet individual needs will prevent the use of more costly services down the road and will improve the quality of life for Iowans who have disabilities.

Recommendation: Provide full access to Medicaid Home and Community-Based Services (HCBS) waiver programs for all eligible Iowa children and adults. Strategies would include:

- Restoring an adequate amount of funding to Iowa Medicaid to reduce the number of individuals on the HCBS waiver waiting list through a supplemental appropriation enacted at the beginning of the 2014 legislative session.
- Developing and implementing a 2-year plan to eliminate all current and future HCBS waiting lists or fund interim services for individuals who are on HCBS waiting lists.

Recommendation: Create a Legislative Study Committee to review Iowa's HCBS waiver system and develop recommendations to improve equity, enhance flexibility, prevent institutionalization, support transitioning, and build community capacity.

Preventing Injuries that Result in Disability

Injury is the leading cause of disability among people between 4 and 44 years of age. It is also a significant cause of disability among seniors and an important cause of secondary disability among those who already have a disability. Investing in injury prevention will yield considerable return to the state.

Recommendation: Expand the Iowa sports concussion law to extend coverage to youth athletes of all ages in all organized sports across the state.

Recommendation: Strengthen Iowa's public health infrastructure for injury and violence prevention by designating adequate state funding to assure the Iowa Department of Public Health can conduct ongoing surveillance, disseminate injury and violence prevention data, coordinate with internal and external advisory groups, develop a comprehensive state plan, and promote use of evidence-based practices for prevention of injuries.

Further information about these recommendations can be found in the full Summit report.

Conclusion

The Summit generated a number of excellent ideas and produced many good recommendations to improve the prevention of disabilities in Iowa. The recommendations included in this summary are those that the Council felt should be a priority for consideration by the Iowa General Assembly. Other recommendations in the report need to be discussed with public and private decision makers who are in a position to act on them. Still others need to be further refined by interagency and consumer groups. The Council is committed to further development of this agenda and its recommendations and looks forward to working with the General Assembly toward that end.

Background

In 2013, the Iowa General Assembly authorized and funded the Iowa Prevention of Disabilities Policy Council (Council) to conduct a summit to develop a state agenda and provide policy recommendations regarding the prevention of disabilities and their secondary conditions. The daylong **2013 Disability Policy Summit: Preventing Disabilities & Ensuring Access to Care** (Summit), took place on December 5, 2013 at the Courtyard by Marriott in Ankeny, Iowa.

More than 130 representatives from government, the public and private sectors and consumers met and worked together to identify priority needs in Iowa and offer consensus policy recommendations.

In addition to the support from the Iowa Legislature, the Council received in-kind support from 15 co-sponsors:

American Academy of Pediatrics, Iowa Chapter
Blank Children's Hospital/Unity Point Health
Brain Injury Alliance of Iowa
Child Health Specialty Clinics
Iowa Department on Aging
Iowa Department of Human Rights
Iowa Department of Public Health
Iowa Developmental Disabilities Council
Iowa Office of Consumer Affairs
Iowa Olmstead Consumer Taskforce
Iowa Medical Society
Iowa Statewide Independent Living Council
State Hygienic Laboratory at The University of Iowa
University of Iowa Children's Hospital, Center for Disabilities and Development
University of Iowa Injury Prevention Research Center

Co-sponsors were instrumental in identifying topical background information, finding potential speakers, and recruiting Summit participants. They also played a role in reviewing the Summit recommendations and report.

Summit Overview

The funding allocated by the Iowa General Assembly was directed to the Council to develop a summit that would "identify cost effective policy options for reaching the greatest number of children and adults in order to eliminate the risk of disability."

The Council, in accordance with its original authorizing legislation, addressed prevention across the life span and all three levels of disability prevention. The Institute for Work and Health at the SSTA Research Center describes these three levels of prevention:

Primary Prevention -- Primary prevention reduces the incidence of disabilities by preventing risk factors that can lead to impairment. If primary prevention efforts succeed, they eliminate any possibility that disability will occur. The goal of primary prevention is to protect healthy people from developing a disease or injury in the first place.

Secondary Prevention -- Secondary prevention targets an existing risk factor and removes or reduces it. When secondary prevention is successful, the disability will not occur. However, since the risk factor did exist and some damage may have been done before secondary prevention began, the impairment may be reduced rather than prevented. The goal of secondary prevention is to halt or slow the progress of disease or a condition in its earliest stages.

Tertiary Prevention -- Tertiary prevention is implemented when a medical condition already exists. It "promotes adjustment to irremediable conditions and minimizes further complications or loss of function" (Scott & Carran, 1987). When tertiary prevention is successful progression along the continuum from pathology to disability is slowed, halted, or even reversed. The goals of tertiary prevention include preventing further physical deterioration, reducing the severity of disability, and maximizing quality of life.

The Council formed a Summit Planning Committee to provide leadership and oversee the planning work by contractors and staff. In choosing the topics to be covered during the Summit, the Committee solicited input from the Council as a whole and other disability partners. Preference was given to topics for which there were significant unmet needs and for which an investment in prevention would yield substantial results. The final three topic areas identified to be addressed during the Summit were:

- **Building inclusive, accessible communities that foster independence and access to healthcare**
- **Supporting children and families to optimize child health and development**
- **Preventing injuries that result in disability**

The Summit was organized into four distinct segments (1) information presentation, (2) legislative priorities and guidance, (3) workgroup deliberations, and (4) summary of workgroup recommendations for all participants.

Information presentation: Participants heard keynote addresses from experts covering all three topics and received additional information that laid the foundation for workgroup deliberations. Keynote addresses included:

- **Building inclusive, accessible communities that foster independence and access to healthcare:** Address given by Thomas Seekins, Ph.D., Director, Research and Training Center on Disability in Rural Communities at the University of Montana
- **Supporting children and families to optimize child health and development:** presentation given by Jennifer McWilliams, M.D., Director of Clinical Services, Division of Child and Adolescent Psychiatry, University of Iowa Hospitals & Clinics

- **Preventing injuries that result in disability:** presentation given by Marizen Ramirez, Ph.D., Associate Director, Injury Prevention Research Center, College of Public Health, University of Iowa

Legislative priorities and guidance: Participants heard from a legislative panel that included: Senator David Johnson, Senator Rita Hart, Representative Art Stead, and Representative Kevin Koester. These legislators discussed the importance of recommendations regarding disability prevention policy in the legislative process and shared their personal goals for the Summit.

Workgroup deliberations: Participants broke into three workgroups organized around the topic areas where discussion was led by experienced facilitators. Each workgroup was tasked with answering the following questions:

1. Which issues identified by the speaker are important to Iowa? Are there other issues that the speaker did not cover that need to be addressed?
2. What is currently being done in Iowa to address the known issues? (Through services, activities, research, policies, etc.)
3. What are the gaps and greatest unmet needs in Iowa?
4. What options are available to address those needs?
5. What are the group's key recommendations to policy makers to address the greatest unmet needs?

Summary of workgroup recommendations for all participants: At the end of the workgroup session, participants reconvened as a large group where the facilitators presented each workgroup's key recommendations. Participants were able to respond to the recommendations, ask for clarification, offer comments on priorities and identify any additional recommendations they thought were missing.

All participants received an opportunity to review and comment on the recommendations by email following the Summit. Co-sponsors were also offered the opportunity to review and comment on the final report.

BUILDING INCLUSIVE, ACCESSIBLE COMMUNITIES THAT FOSTER INDEPENDENCE AND ACCESS TO HEALTHCARE

Overview

Disability currently affects over 5.3% of Iowa children between the ages of 5 and 17 and 19% of non-institutionalized adults. These Iowans have a disability because they are limited in their ability to participate in and contribute to society due to difficulty with mobility, performing personal care, communicating, learning, and/or working.

Iowa data show that, compared to persons without disabilities, those with disabilities experience more adverse social conditions that are linked to poor health outcomes. They are more likely to:

- report that their health is no better than fair to poor,
- have high blood pressure,
- experience depression,
- be smokers,
- be inactive,
- be obese,
- go without needed health items due to cost, and
- spend less on basic needs, such as food, in order to pay for needed health services.

Without access to appropriate health promotion and health care services, people with disabilities are at increased risk of developing a secondary disability that that can add to their level of disability and increase their level of dependence on specialized services.

Health reform has brought about several important changes affecting people with disabilities. Insurers are no longer able to deny coverage to an individual with a disability because of a pre-existing condition, and the act's essential benefits requirements are increasing access to additional types of needed health services for many people with disabilities. The changes in the health care system brought about by health reform are intended to place a greater emphasis on prevention and health promotion, patient-centered outcomes, shared decision making and care coordination. Reimbursement will be based on outcomes rather than number of services delivered. Each of these changes has the potential of improving health care for people with disabilities. However, it will be important for disability advocates to be at the table to assure that programs are designed in a way that meets their needs.

Just because an individual has a condition or impairment such as cerebral palsy, limb loss, visual impairment, or heart disease does not necessarily mean that individual has a disability. Disability relates to an individual's ability to function and perform major life activities. For many individuals with physical impairments, they will not be considered disabled if they can fully access community environments, activities, and services. Although the Americans with Disabilities Act (ADA) has brought about many improvements in access, there is much more to do. Iowans report continuing problems with access, and a study being conducted by the University of Montana of communities of all sizes around the country is showing very poor access scores in the nation's rural communities. Community members with disabilities should form partnerships within their communities and begin to assess access, identify high-priority needs, and develop plans to address those needs. A handful of Iowa communities have already started this type of process and are beginning to see improvements.

Assessment of the Issue in Iowa

The workgroup discussed the data available on health disparities for Iowans with disabilities, including a multi-year study recently completed by the Iowa Department of Public Health (IDPH) that looked at overall health, behavioral risk factors, and the use of preventive health services for non-institutionalized Iowa adults with disabilities. The study provided data for the state as a whole and for each of Iowa's 99 counties. Currently, IDPH has a time-limited grant from the Centers for Disease Control and Prevention to improve access to and participation in public health programs, particularly health promotion and preventive health services. The workgroup felt that IDPH, with the county data now at hand, needed to require local public health agencies to address the needs of people with disabilities in the development of their local health improvement plans. Members also agreed there was a need to expand current activities to additional IDPH programs and continue this work after the end of the federal grant.

Workgroup members felt that access to appropriate, quality health care continued to be a problem in Iowa for people with disabilities. Barriers were identified as: (a) transportation, (b) accessible facilities and equipment, (c) inadequately trained office staff and problematic office procedures, (d) inaccessible written materials, (e) insufficient examination time, (f) lack of care coordination of treatment for multiple health issues, (g) poor health provider communication skills, and (h) unavailability of specialty care. The workgroup discussed how current Iowa health initiatives could be better geared to meet the needs of people with disabilities and noted that it would be important to monitor how people with disabilities fared within Iowa's Accountable Care Organizations and Iowa Health and Wellness program. They also felt Iowa needed to expand telehealth services to better meet the needs of Iowans with disabilities.

The workgroup identified a need to effect change in how health care practices accommodated and communicated with their patients with disabilities, noting that it might be advantageous to bring consumers and providers to the table to dialogue about the issues and develop some basic strategies that could be promoted in practices across the state. Members believed there was a need to expand training of health care providers in communication with and accommodation for patients with disabilities. The workgroup recognized the health provider training initiative being undertaken by the Center for Disabilities and Development as a model that could be expanded across the state.

The workgroup discussed the difficulty people with disabilities have in making major life transitions when service needs and expectations change. They believed there was a need to begin transition planning for children with Individual Education Plans at an eaarlier age to allow time to begin thinking about appropriate expectations and to prepare for service changes, including changes that occur when entering the adult health care services system. Members also identified the need to improve transitions for people with disabilities from the hospital back into the community. Members talked about the fact that people with disabilities all too often ended up receiving no services, inappropriate services, or overly restrictive services when they were discharged from the hospital. They agreed that hospitals needed tools, protocols and better linkages to help guide them in the transitioning process.

Workgroup members agreed across the board that there was a need to jump start implementation of the American with Disabilities Act (ADA) in Iowa. They concurred that although progress had been made, access to both public and private services as well as housing was still a problem in

most Iowa communities, and particularly in rural communities. They suggested the development of an Iowa initiative to improve community access modeled after the Blue Zones initiative.

Finally, workgroup members spent a considerable amount of time discussing the reform of Iowa's system of services for individuals with significant disabilities. Members agreed that progress was being made in regionalizing the state system, eliminating the county of legal settlement requirement, and adopting a set of core services for people with disabilities that would be available to all eligible individuals across the state. However, the workgroup noted that services would still not necessarily be available to individuals with developmental disabilities (including autism) and those with brain injury. Related issues discussed by the group included (a) waits of up to 2 years for eligible individuals to receive Iowa Home and Community Based Services (HCBS), (b) the structure of Iowa's current waivers that don't allow enough flexibility to meet individualized needs, (c) lack of investment in programs geared to helping people with disabilities gain employment, and (d) little coordination between Iowa's health and disability services systems to meet the needs of individuals with disabilities.

Workgroup Recommendations

Improving Health and Providing Access to Healthcare for People with Disabilities

Recommendation: Expand and improve state and local public health services to reduce known health disparities for Iowans with disabilities. Strategies would include:

- Ramping up state-level messaging on health and wellness for persons with disabilities
- Routinely conducting surveillance of health disparities for persons with disabilities and disseminating the data collected to state policy makers, local health departments, and advocacy groups.
- Promoting the use of best practices to reduce disparities
- Requiring local public health agencies to assess the health needs of residents with disabilities and plan to address unmet needs as part of the local Health Improvement Process Planning

Explanation: The Iowa IDPH has received a grant from the Centers for Disease Control and Prevention that has allowed it to start the process of reviewing the accessibility of public health information and environments and to conduct a review of selected programs to determine better ways to design services to include people with disabilities. These activities need to continue beyond the life of the grant and to be expanded to additional IDPH programs. Since IDPH now has multi-year county level data on health disparities for Iowans with disabilities it is time to require local public health agencies to assess the needs of their residents with disabilities and to develop plans to address unmet needs.

Recommendation: Develop policies and initiatives focused on improving access to health care services for people with disabilities. Strategies would include:

- Expanding the Medicaid Health Home program to additional populations with disabilities
- Assuring that Iowa Accountable Care Organization (ACO) criteria include guidance regarding the categories of specialists required in an ACO network in order to provide the full spectrum of benefits to meet the wide range of needs of patients with disabilities and chronic conditions and assuring that performance is judged based on measures of patient functional status as well as acute medical care measures

- Amending the Iowa Health and Wellness Plan to make non-emergency transportation for routine medical visits a covered service
- Providing consistent insurance coverage for telehealth services through both Medicaid and private insurance.

Explanation: Access to appropriate, quality health care continues to be a problem in Iowa for people with disabilities. Some of the barriers identified include: (a) transportation to medical appoints, (b) insufficient examination time, (c) lack of care coordination for treatment of multiple health issues, and (d) unavailability of specialty care. Each of the strategies listed above would reduce these barriers and improve health care for Iowans with disabilities.

Recommendation: Convene a workgroup composed of public and private providers, funders and consumers to identify barriers to providing accessible health care environments and delivering preventive health services for Iowans with disabilities; develop recommendations to eliminate the identified barriers.

Explanation: Iowans with disabilities continue to report barriers to receiving the health care they need. These barriers include (a) inaccessible facilities and equipment, (b) inadequately trained office staff, (c) office procedures that are not adapted, (d) inaccessible written materials, and (e) insufficient examination time. Additionally, a study of the preventive health care received by Iowans with disabilities on Medicaid found low rates of preventive health care visits for recipients over 44 years of age and near non-existent rates of preventive health screenings for cancer. A workgroup composed of the key stakeholders will promote dialogue and facilitate the development of consensus recommendations to improve access to care.

Recommendation: Develop policies and initiatives to improve health care provider communication with patients who have disabilities. Strategies would include:

- Expansion of the Center for Disabilities and Development health care provider pre-service training curriculum to additional nursing, physician, physician assistant, and dental training programs in Iowa
- Consideration of a requirement that health care providers receive training and/or demonstrate competency in communicating with patients with disabilities as a part of the professional licensure process
- Development and dissemination of a best practices "toolkit" on communication with patients with disabilities to health care practices throughout the state
- Assure appropriate access to interpreters and/or consider repeal of Iowa's English Only law and assure availability of materials and signage in other languages

Explanation: Recent research has demonstrated the important role communication between the health care provider and patient plays in gaining compliance with effective care plans. People with disabilities face many barriers to communication that health care providers need to understand and be equipped to address.

<u>Increasing Community Inclusion and Participation for People with Disabilities</u>

Recommendation: Create an ACCESS Iowa initiative to promote greater participation by people with disabilities in Iowa communities. The initiative would promote both:

- Access to state and local governmental environments, activities and services, to assure:
  - Physical access to buildings, equipment and services;

- Program access through materials, signage and 508 compliance;
- Participation of appropriate representatives of people with disabilities on relevant state and local boards, councils, and commissions;
- Access afforded by government contractors and subcontractors;
- The accuracy and relevancy of current code language; and
- The adequacy of the resources provided to governmental entities to allow and encourage them to become compliant.

- Ways to improve access to all community environments, activities, and services including:
  - Creating a simple Accessibility Report Card for use in assessing a community's accessibility;
  - Facilitating the creation of Access for All committees composed of consumers and other stakeholders to advise communities about priorities and methods to improve access;
  - Promoting implementation of existing initiatives like the Complete Streets program by Iowa communities;
  - Disseminating information about "low cost" solutions to address identified barriers to participation;
  - Identification of existing funding resources to support making changes to the environment; and
  - Consideration of a the creation of a state grant program to assist rural communities in completing accessibility assessments, developing plans of action, and funding of selected projects.

Explanation: About 18% of non-institutionalized Iowa adults report having some type of disability. People with conditions such as cerebral palsy, limb loss, visual impairments and heart disease will not necessarily be disabled if they can fully access community environments, activities and services. Although the ADA has brought about many improvements in access, there is more to do. Iowans with such conditions report continuing problems with access and a recent study conducted by the University of Montana of communities around the country showed very poor access scores in rural communities.

Recommendation: The State should create a refundable income tax credit for up to 75% of the costs incurred for an individual to retrofit a primary residence to accommodate aging and disability access.

Explanation: Many of the falls that occur among those with disabilities, chronic health conditions, and the elderly take place in the home. Retrofitting a home to accommodate a disability can be a costly undertaking. Providing a tax credit to assist individuals in retrofitting their primary residence would increase safety and reduce the likelihood of injury due to falls. It would also increase the length of time an individual could live with some degree of independence in his/her home rather than in an institution.

Improving Life Transitions for People with Disabilities

Recommendation: Through the educational system, strengthen the Individuals with Disabilities Education Act transition planning process to develop skills for living, learning and working in the community to instill the expectation for independent, healthy, community-based living and initiate transition planning at an early age.

Explanation: In many cases transition planning is not started until the later teen years and it often does not include planning for health and health care transitioning. As a result, many students do

not envision and set goals to allow them to gain competitive employment and live more independently in the community.

Recommendation: Improve hospital discharge planning for patients with disabilities, chronic conditions and significant injuries to assure that they receive necessary assessments and are linked with appropriate community services that will maximize their independence, provide a safe environment, and prevent re-hospitalization. Strategies would include:

- The development of a protocol and "tool box" to assist hospital discharge planners complete assessments, determine service needs, and link the patient with appropriate resources;
- Design a system that links knowledgeable care coordinators from groups such as Centers for Independent Living, Area Agencies on Aging, county case managers, and disability navigators into discharge planning at early stage; and
- Identification of opportunities provided through health reform to create and fund these activities.

Explanation: Hospital discharge planners all too often do not have the knowledge or tools necessary to complete functional needs assessments and locate appropriate services in the community, particularly in rural communities. These planners also have very little time before discharge to complete the necessary tasks. As a result patients with disabilities all too often end up receiving no services, inappropriate services, or overly restrictive services upon discharge from the hospital resulting. Implementing the strategies listed above would facilitate patient recovery, promote independence and prevent re-hospitalization.

<u>Increasing Employment Among People with Disabilities</u>

Recommendation: Maximize quality of life via enhanced inclusive, integrated, community-based employment and day services instead of segregated services based in congregate settings.

Explanation: According to the 2011 report of the Intellectual and Developmental Disabilities Workgroup, the vision for employment services should be well articulated and focused on a Work First policy that expects that people with developmental disabilities will earn wages at or above minimum wage and will include benefits commensurate with employees without disabilities. This can be accomplished through balancing current funding methodologies and structures to encourage community-based integrated services. The Iowa Department of Human Employment Services workgroup is currently developing recommendations to meet this goal. Those recommendations should be supported.

Recommendation: Provide basic employment and benefits planning information to all Medicaid members with disabilities to maximize employment and health outcomes and reduce health care costs.

Explanation: The Department of Human Services does not routinely provide information about employment and benefits planning to Medicaid recipients such as those who receive Supplemental Security Income or those on the Medicaid for Employed People with Disabilities program. Making this simple change in the dissemination of employment information would help to promote a Work First Policy.

Recommendation: Increase state appropriations to maximize Federal Title I funding that helps support Vocational Rehabilitation (VR) employment services.

Explanation: Iowa Vocational Rehabilitation Services (IVRS) currently does not draw down all of the Title I Federal funds available to Iowa under the Rehabilitation Act because of inadequate state matching funds. This has meant that less than optimal funding is available to support VR employment services such as customized employment and skills training.

SUPPORTING CHILDREN AND FAMILIES TO OPTIMIZE CHILD HEALTH AND DEVELOPMENT

Overview

Adverse Childhood Experiences (ACEs) are stressful or traumatic experiences including abuse and a range of family dysfunction issues. Studies conducted in the past 15 years show that ACEs are strongly related to the adoption of risky health behaviors; the development of disease, disability and social problems; and early death in adulthood. The impact of ACEs on adult health status is not only strong but it is cumulative.

Extensive research on the biology of stress shows that healthy development can be derailed by excessive or prolonged activation of the body's stress response systems, with damaging effects on learning, behavior, and health. The experience of toxic stress in childhood can result in a weak foundation and disrupted development in later developmental stages. There is also a strong relationship between ACEs and adult mental health problems.

The national ACE Study surveyed patients regarding seven adverse childhood experiences and compared those with 10 risk factors for the leading causes of morbidity, disability, and death, as well as seven significant causes of disability and mortality in the US. The results showed that as the number of adverse childhood experiences increased so did the prevalence of all 10 risk factors. There was also a significant relationship between the number of adverse childhood experiences and severe disease conditions including heart disease, cancer, COPD, hepatitis and skeletal fractures.

Iowa's 2012 ACE Study looked at the prevalence of individual ACEs reported by Iowa adults. Fifty five percent of Iowa adults reported having experienced at least one ACE. Overall, 34% of adults experienced two or more ACEs, or 1 in 3 Iowans. Childhood emotional abuse was the most common ACE, reported by 28% of adults, followed by adult substance abuse (26%) and parent separation or divorce (22%). The study suggested that a steady increase in poorer self-rated health is associated with a higher number of ACEs, and a striking number of adults who reported facing limitations in activity due to their perceived poor health status. The odds of having a risk factor were quadrupled for Iowa adults having three or more ACEs. As the number of ACEs increased so did the prevalence of 10 serious health conditions, clinical depression and the number of poor mental health days in a month.

Early identification and intervention are the keys to preventing adoption of risky health behaviors, the development of disease, disability and social problems and early death in adulthood. To begin to address ACEs in Iowa, health care providers, educators and human service providers need to understand the effects of ACEs on an individual's future health and disability. They also need to have the skills to know how to identify those individuals who are having adverse childhood experiences. At the state level, Iowa needs to integrate a trauma-informed approach across child and family serving systems and organizations. It will also be important to support the development or expansion of effective intervention services across the state.

Assessment of the Issue in Iowa

The workgroup discussed Iowa's system of care looking at its current ability to and success in identifying health problems, developmental challenges and adverse childhood experiences as early as possible and then providing effective intervention services to prevent or reduce disabilities. The group

acknowledged the work currently being funded by Iowa Medicaid that trains health care providers in early childhood screening for developmental, social and behavior issues and therapists to treat the young at-risk child. They noted that Iowa is currently providing services to families with young children across the state through Iowa Community Empowerment. Iowa has created 1st Five and Project Launch to address the need for earlier identification and intervention of young at-risk children; however, neither 1st Five nor Project Launch is available statewide. The group felt that the Iowa ACEs Study underscored the need to expand Iowa's system of care to improve early identification and intervention for children of all ages. The group suggested that Iowa create develop a "1st Twenty" initiative.

Workgroup members believed that access to health care for all Iowa children, including those at-risk and those with disabilities, continued to be an issue in Iowa. The group discussed the barriers faced by children living in Iowa's most rural areas and those with disabilities who had a greater need for specialty care. The group felt that telehealth was the most practical and effective strategy for ensuring access to health care and community-based services for children living in rural or underserved areas of the state. They noted that telehealth services were still not consistently covered by all insurers in Iowa. There continues to be a great deal of variability among insurers as to the types of services that are covered and the specific professionals who are approved to be reimbursed for providing telehealth services.

Another issue identified and discussed by the group was the need to reach more children and improve the services offered through Iowa Medicaid's Home and Community Based Services waiver programs. Members indicated that some children had been waiting for waiver services for two years and felt that immediate action was needed to decrease if not eliminate the state's current waiver waiting lists. They also felt that Iowa's waivers were not structured in a way that allowed for flexibility in meeting individual child and family needs.

Finally, the workgroup identified a number of Iowa needs related to secondary and tertiary level prevention including the need to (a) expand Iowa law addressing health care coverage for autism to include both public and private insurers as has been done in many states, (b) improve transitioning services for youth with disabilities to better address adult employment and health planning issues at an earlier age, (c) increase funding for workforce training, recruitment and retention of needed health professionals, and (d) increase support for childcare and after-school care, especially for children with behavioral issues and other special needs.

Workgroup Recommendations

<u>Improving Early Identification and Intervention</u>

Recommendation: Provide access for all Iowa children to early identification and early intervention services that can prevent or reduce serious disabilities.

- Implement the 1st Five Healthy Mental Development Initiative for children ages 0-5 in all Iowa counties; and
- Invest in a coordinated system of childhood services that provides individualized developmental and behavioral interventions for children with disabilities and those at high risk for disabilities.

Explanation: Identifying health problems and developmental challenges as early as possible offers the best hope for successful intervention to prevent or reduce disabilities. To accomplish this, Iowa needs a coordinated system of early childhood services that fills existing gaps in care and integrates services seamlessly across the health care, education, and social service systems. Implementing the 1st Five Healthy Development initiative for young children (ages 0-5) in all Iowa counties can contribute to early identification and coordination of care as long as access to effective evidence-based interventions is made available to all children who are at risk for long-term problems. In addition, the need for accurate identification and effective intervention for learning and behavior problems and adverse childhood experiences requires a coordinated system that does not stop at age 5. Iowa needs a "1st Twenty" initiative that ensures that all children and youth through age 20 will have access to the programs and services they need to become happy, healthy, and productive adults.

Recommendation: Expand current health care provider training initiatives to address identification of autism and other disabilities, screening for adverse childhood experiences, screening for behavioral health concerns in adolescents, and helping adolescents manage the transitions between child and adult care.

Explanation: Iowa's current health care provider training initiative, that is funded by the Iowa Medicaid Enterprise, is focused on surveillance and screening of the young child for developmental, social-emotional and behavioral issues. Looking at the data now available through the Iowa ACE Study, it is time to expand that initiative to better address all social determinants of health among Iowa children of all ages.

<u>Improving Availability and Coordination of Services</u>

Recommendation: Provide effective care coordination and intervention for children of all ages.

This recommendation can be achieved by:

- Improving collaboration and sharing of information freely across agencies and programs, including health care, education, and human services.
- Identifying and filling gaps in service delivery systems for children.
- Implementing and expanding "health homes" that ensure appropriate care and programming.
- Providing transition planning for children with disabilities who are moving to adult systems of care.

Explanation: Iowa needs to take a systematic look at its entire system of childhood services for children of all ages, including those with disabilities, to streamline the system, increase coordination, identify and fill in gaps in services and promote a healthy transition into adulthood.

Recommendation: Provide additional program and funding support for childcare and after-school care to.

- Raise the child care assistance eligibility level from 145% of Federal Poverty Level to 155%.
- Increase provider reimbursement rates to the 2008 market rate.
- Extend the continuous eligibility reapplication time from 6 to 12 months.
- Allow for the combination of school hours and work hours to meet the 28 hour requirement to be eligible for child care assistance.

Explanation: Iowa's child-care assistance program helps low-income parents pay for care while they work or attend school. The income eligibility limit of 145 percent of poverty is among the lowest in the

U.S – only 6 states have a ceiling equal to or lower than 145 percent; 19 states have a threshold at or above 200 percent. Families whose income rises just slightly above the cutoff actually find themselves worse off, as they are suddenly responsible for the entire cost of child care. Even after two modest increases, payments to Iowa providers under child-care assistance (set just below the 75th percentile of the 2006 market rate) remain below national standards and what it takes to pay a living wage. Some providers may choose to stop serving children on childcare assistance because they can no longer do so. Families in Iowa who qualify for child care assistance must re-apply every 6 months. Authorizing subsidies for longer periods of time would help families have sustained access to child care settings. Someone who has the skills appropriate only for low-wage jobs but wants to pursue post-secondary education will typically need to work part-time and attend school part time. But such a person, if not in the FIP (family investment) program, would be required to work 28 hours per week in addition to class and out-of-class schooling hours. Allowing for the combination of school and work hours to meet the 28 hour requirement would place more realistic demands on a person's time and allow individuals to pursue education by not forcing a choice between family, work, and school.

Improving Access to Quality Health Care Services

Recommendation: Mandate insurance coverage for autism spectrum disorders and require coverage for applied behavior analysis without limits on age.

Explanation: Applied behavior analysis (ABA) is supported by strong scientific evidence for the treatment of social and behavioral problems in children with autism spectrum disorders. The Iowa Code currently mandates that insurance companies offering health plans funded by the State of Iowa must provide coverage for children with autism, including coverage for ABA up to specified annual limits. To assure appropriate behavioral care for children with autism, the current law should be broadened to include all Iowa insurance carriers. The majority of states in the U.S. have already enacted similar laws providing an insurance mandate of this type.

Recommendation: Support educational loan repayment programs and other initiatives that increase the availability of health care providers in underserved regions and in understaffed disciplines.

PREVENTING INJURIES THAT RESULT IN DISABILITY

Overview

Injury is the leading cause of disability among people between 4 and 44 years of age. It is also a significant cause of disability in older adults and an important cause of secondary disabilities among those who already have a disability. Up to 90% of injuries are preventable.

Injuries affect the lives of all Iowans, regardless of age, race, gender, or size of county. In Iowa, injury is equal to cancer in causing years of productive life lost. Unintentional injury is the 5th leading cause of death for all Iowans. Unintentional injuries are the leading cause of death for Iowans between ages 1 and 34. Suicides and/or homicides also rank among the top 5 leading causes of death for Iowans between ages 1 and 54. For Iowa adults aged 65 and older, falls are the leading cause of nonfatal injury and death. Injuries result in more than 17,000 hospitalizations in Iowa each year and more than 250,000 emergency visits.

Motor vehicle crashes are the leading cause of injury related disability nationally and in Iowa. Falls are the leading cause of traumatic brain injury. Data show that 20 - 30% of people who fall suffer moderate to severe injuries such as hip fractures or head traumas. In Iowa, injuries and deaths from falls have risen 20% over the last decade. Iowa's death rate from falls – 9.4 per 100,000 - is higher than the U.S. rate of 7.8 per 100,000. The total cost of hospitalizations in Iowa due to falls is $135 million per year; the average charge per hospitalization for a fall is around $26,200.

Sports-related injury has become recognized as an important cause of disability in the past decade. Research has linked concussion, particularly repeated sports-related concussions, with cognitive impairments, disability, and even premature death in later life. Approximately 40 million children and youth 18 years old and younger participate in organized sports in the U.S. Children are participating in organized sports at a much younger age. Many elementary schools are now fielding tackle football teams as early as the 3rd grade. More than 3.5 million children between the ages of 5-14 are injured nationally each year while participating in sports activities. Sports-related concussions are estimated at 300,000 per year, with over 135,000 in high school sports.

Injuries can be prevented through engineering, education and enforcement. Research shows that motor vehicle crashes can be decreased significantly through legislation and enforcement of passenger safety, drunk driving and motorcycle helmet laws. For falls, the number of injuries can be reduced through the use of routine falls risk assessments of at-risk groups by health care and other service providers and the availability of resources such as adaptive equipment, home modification and community-based Complete Streets programs. Permanent damage from sports-related concussions among youth can be reduced through requirements for parent education, training of coaching staff and regulations that require the removal of a child who displays concussion symptoms from the activity and the prevention of the premature return of the child to the activity.

Assessment of the Issue in Iowa

The workgroup reviewed Iowa laws and enforcement related to the prevention of motor vehicle accidents: They indicated that Iowa:

- Had a primary seat belt law,

- Had a child passenger safety law, although the law does not meet the standards recommended by the American Academy of Pediatrics (AAP) and the National Highway Safety Administration,
- Had a graduated licensing law as of last year, although it could be strengthened by increasing the limits on driving during certain times of the day, and
- Did not have a universal helmet law.

Members noted that Iowa does track child passenger safety compliance through an annual study done by the University of Iowa Injury Prevention Research Center and that five Iowa communities have Safe Kids Coalitions which provide awareness, education and policy advocacy.

Iowa also has a statewide Falls Prevention Coalition that has been meeting to gather information about the prevalence and impact of fall injuries in Iowa and to identify effective strategies to prevent falls from occurring. The workgroup noted that there is a need to develop a focused effort to disseminate information about falls prevention best practices to Iowa providers and consumers. Members also felt Iowa needed to provide financial assistance to assist consumers in making modifications to their homes to prevent falls.

The workgroup discussed sports-related concussion noting that Iowa had passed a bill in 2012 that increased protection of student athletes in grades 7-12 by requiring training for coaches to recognize the signs, symptoms and behaviors of brain injury in youth athletes. The bill also required that athletes suspected of having a concussion be removed from play and only be allowed to return when cleared by a health professional. Given the number of youth athletes who are participating in school sponsored contact sports activities in grade school and the number of athletes who participate in sports sponsored by other organizations, the workgroup felt there was a need to amend the current law to extend the same coverage to those athletes.

Preventing injuries to individuals with disabilities during emergency or disaster situations is currently being studied by the Iowa Injury Prevention Research Center, and training about personal preparation for emergencies is being provided to consumers and caregivers through a grant from the Centers for Disease Control and Prevention. Consumers in the workgroup felt there was also a need address accessibility issues at the county and state systems levels. Members reported problems such as media failing to use closed captioning to provide information about emergencies to individuals who are deaf. Also, they noted that equipment for use during an emergency, (e.g., vibrating alarm systems or flashing strobe lights), could be expensive and that funding might be needed to increase its availability.

The workgroup felt strongly that Iowa needed to develop a more focused, coordinated effort to address the prevention of injuries on a statewide basis. Currently, 41 states have an injury and violence prevention program. Twenty of those states receive federal funding but most of the others receive funding though state general funds. Iowa is not one of the states that has an injury and violence prevention program. The advantages a dedicated program brings would be the ability for Iowa to do ongoing surveillance to monitor trends in injury and violence, use the data to establish priority areas and plan for the best use of limited resources. Additionally, a broader "injury and violence prevention stakeholder group" would serve to bring many constituent groups together with a single vision and focus.

In addition, the workgroup identified a number of Iowa needs related to secondary and tertiary level prevention including the need to (a) improve discharge planning for those who have been hospitalized due to falls and traumatic brain injuries to assure that a functional assessment has been completed and that the individual and family have been linked with the appropriate level of care, (b) fully cover telehealth services, (c) eliminate the waiting list to receive Brain Injury Home and Community Based waiver services, and (d) build more flexibility into the Home and Community Based Services waivers to provide more individualized services.

Workgroup Recommendations

Preventing Motor Vehicle Injuries

Recommendation: **Amend the Iowa child passenger safety law to make requirements in line with recommendations from the American Academy of Pediatrics and the National Highway Safety Administration.**

Current Iowa Law	Best Practice Recommendations
Children must ride in a rear-facing safety seat until 1 year of age AND weigh at least 20 pounds.	Children must ride in a rear-facing child safety seat until the maximum weight limit of the safety seat is reached (up to 30 or 35 lbs., depending on the seat).
Children must ride in a child safety seat or booster seat through age 5, in accordance with manufacturer's directions.	Children should be restrained in a 5-point harness system until the maximum weight limit for the seat is reached (usually 40 lbs., although some are now up to 60-65 lbs.).
Children must be in a booster seat or seat belt between the ages of 6 and 11, regardless of their seating position within a vehicle.	At maximum harness weight, a child should graduate into a booster seat. They should ride in a booster seat until their knees bend over the edge of the vehicle seat and their feet touch the floor while sitting all the way back.
Rear seat occupants up to age 18 must be secured by a safety belt.	Vehicle occupants under age 18 who do not require a child safety seat or booster seat must be secured by a safety belt in all positions within a vehicle.

Explanation: Best practices for child passenger safety as defined by the American Academy of Pediatrics (AAP) have changed in recent years. Iowa's law should be amended to bring it into line with known best practices. A new report from the Centers for Disease Control and Prevention found that "Child passenger restraint laws that increase the age for car seat or booster seat use result in more children being buckled up. Among five states that increased the required car seat or booster seat age to 7 or 8 years, car seat and booster seat use tripled, and deaths and serious injuries decreased by 17%."

Recommendation: Enact a universal helmet law in Iowa.

Explanation: People of all ages driving motorized vehicles (including motorcycles, scooters, mopeds and ATVs), as well as those riding bicycles should be required to wear a helmet as a proactive way to prevent head injuries due to accidents. On average, states with a universal helmet law save 8 times more riders' lives per 100,000 motorcycle registrations each year, compared to states without a helmet law, and save 3 times more riders' lives per 100,000 motorcycle registrations each year, compared to states with a partial helmet law. Economic costs saved in states with universal helmet laws were, on average, nearly four times greater per registered motorcycle than in states without such a law. While opponents argue that requiring helmet use restricts individual freedom and choice, the costs associated with the increased death and disability pose a significant burden on the state.

Preventing Concussions

Recommendation: Expand the Iowa sports concussion law to extend coverage to youth athletes of all ages in all organized sports across the state.

Explanation: Currently Iowa law applies only to students in grades 7-12. Many younger children now participate in contact sports and many children of all ages participate in sports organized by recreation departments, municipalities, and other organizations. These children should be afforded the same protection as those in junior and high schools.

Recommendation: Pass a law that would prohibit participation in contact sports for children under the age of 14.

Explanation: Children and youth under the age of 14 do not possess the physical capabilities or decision-making ability to safely participate in contact sports.

Preventing Injuries for People with Disabilities during Emergencies

Recommendation: The State should allocate adequate funding through a scaled income voucher system to provide emergency equipment to deaf and hard-of-hearing people who need it during emergencies including disasters.

Explanation: Safety equipment for the deaf and hard of hearing can be quite expensive. For many, the cost of life-saving equipment (e.g., vibrating equipment or flashing lights) that would inform them of a disaster is out of reach. Having access to this equipment will help to prevent injuries that cause further disabilities and will save lives.

Recommendation: Request the Iowa Department of Homeland Security educate the news media and promote enforcement of the 21st Communication Act that requires the media to provide remote communications access real-time translations (CART) to ensure that there is closed captioning for emergencies and disasters.

Explanation: Media are not currently doing this routinely or uniformly throughout the state. Lack of adherence to the law is putting many of those with disabilities including those who are deaf or hard of hearing in adverse situations that could cause injury or death. Assuring all media are familiar with the requirements and monitoring adherence to the law would help prevent these situations.

Creating a Systematic Approach to Preventing Injuries in Iowa

Recommendation: Strengthen Iowa's public health infrastructure for injury and violence prevention

by designating adequate state funding to assure the Iowa Department of Public Health can conduct ongoing surveillance, disseminate injury and violence prevention data, coordinate with internal and external advisory groups, develop a comprehensive state plan, and promote use of evidence-based practices for prevention of injuries.

Explanation: Injury is the leading cause of disability among those between 4 and 41 years of age. It is also a significant cause of disability among older Iowans and an important cause of secondary disability among individuals with disabilities. Currently, 41 states have an injury and violence prevention program. Twenty of those states receive federal funding to support their program; most of the others receive funding from their state's general fund. Iowa is not one of these 41 states. Consequently, there is little infrastructure to assure ongoing surveillance, prioritize and focus areas of need, and disseminate data or best practices for prevention. The Office of Disability, Injury & Violence Prevention within the Iowa Department of Public Health serves in a "coordinating" role within the department, but has no ongoing source of funding to assure the visibility and importance of injury and violence prevention as a public health issue.

CROSS-CUTTING RECOMMENDATIONS

All three workgroups discussed and identified a priority need to further develop Iowa's system of community-based services and supports for people with significant disabilities to provide equity and access to the range of services required to prevent further physical deterioration, reduce the severity of disability, and maximize each individual's quality of life. The three workgroups jointly issued the following priority recommendations:

Increasing Access to Health Care for People with Injuries, Disabilities and Chronic Health Conditions

Recommendation: Provide consistent insurance coverage for telehealth services by legislatively requiring both Medicaid and private insurance companies to cover telehealth services.

Explanation: Telehealth/telemedicine is the most practical and effective strategy for ensuring access to health care and community-based services in rural or underserved areas across the state. Use of telehealth has been shown to reduce rates of hospitalization and re-hospitalization, to prevent small problems from becoming serious disabilities, and to overcome geographic barriers to receiving quality care. Telehealth has proven effective in providing consultation to patients and local providers, home monitoring, behavioral services including applied behavior analysis (ABA), medication management, and psychotherapy. Insurance coverage for telehealth is increasing in Iowa, but there are still inconsistencies in terms of the types of services that are covered and the specific professionals who are approved as reimbursable for delivering telehealth services. As recommended by the American Telemedicine Association, coverage by commercial insurers and public programs should be provided for services delivered through telehealth to the same extent that these services are covered when they are provided in person.

Improving Iowa Services for People with Disabilities

Recommendation: Provide full access to Medicaid Home and Community-Based Services (HCBS) waiver programs for all eligible Iowa children and adults. Strategies would include:

- Restoring an adequate amount of funding to Iowa Medicaid to reduce the number of individuals on the HCBS waiver waiting list through a supplemental appropriation enacted at the beginning of the 2014 legislative session.
- Developing and implementing a 2-year plan to eliminate all current and future HCBS waiting lists or fund interim services for individuals who are on HCBS waiting lists.

Explanation: Having individuals with disabilities on waiting lists for services creates additional problems for service systems, medical systems, families, and caregivers that are much more costly than providing services as part of the waiver.

Recommendation: Create a Legislative Study Committee to review Iowa's Home and Community-Based Services (HCBS) waiver system and develop recommendations to improve equity, enhance flexibility, prevent institutionalization, support transitioning from institutional settings, and build community capacity.

The Committee should consider the following issues:

(1) Ensuring access to necessary HCBS programs for people with Developmental Disabilities (including Autism), Brain Injury, and other disability populations;
(2) Combining current waivers into broader, more flexible waivers that employ a service delivery model based on functional needs.
(3) Creating options to reimburse immediate family members for care of a relative with a disability through the Consumer Choices Option or other methods;
(4) Increasing options for funding to support individuals transitioning from an institution into the community;
(5) Provider reimbursement levels and methodologies, including consideration of (a) building in a COLA (cost of living adjustment) for HCBS waiver programs similar to the current practice of "rebasing" for nursing homes, and (b) development of an incentive payment structure focused on long-term outcomes; and
(6) Increasing or eliminating waiver caps for both funding and the number of individuals who are eligible for services.

Explanation: Iowa is in the midst of reforming its system of services for people with disabilities. It is important that the HCBS waive programs are designed to allow flexibility to meet the needs of each individual and/or family. Providing adequate and timely services that meet the individual needs of individuals will prevent the use of more costly services down the road and will improve the quality of life for Iowans who have disabilities.

Appendix A:
2013 Disability Policy Summit Agenda

Disability Policy Summit:
Preventing Disabilities and Ensuring Access to Care

Preventing disabilities is everybody's business – Come join the conversation!

8:00 a.m. – 4:30 p.m., December 5, 2013
Courtyard by Marriott, Ankeny, Iowa

AGENDA

8:00 a.m.	**Registration**
8:30 a.m.	**Welcome** Gerd Clabaugh, Deputy Director, Iowa Department of Public Health Theresa Armstrong, Bureau Chief, Iowa Department of Human Services, Division of Mental Health and Disability Services
8:40 a.m.	**Overview of the Summit and Participant Charge** Cheryll Jones, Chair, Prevention of Disabilities Policy Council
8:55 a.m.	**Presentation: Building Inclusive, Accessible Communities that Foster Independence and Access to Healthcare** Thomas Seekins, Ph.D., Director, Research and Training Center on Disability in Rural Communities, University of Montana
9:55 a.m.	**Break**
10:05 a.m.	**Presentation: Supporting Children and Families to Optimize Child Health and Development** Jennifer McWilliams, M.D., Director of Clinical Services, Division of Child and Adolescent Psychiatry, University of Iowa Hospitals & Clinics
11:05 a.m.	**Presentation: Preventing Injuries that Result in Disability** Marizen Ramirez, Ph.D., Associate Director, Injury Prevention Research Center, College of Public Health, University of Iowa
12:05 p.m.	**Lunch**
	Legislative Response Panel (12:30 p.m. – 1:15 p.m.) Senator Rita Hart, Senator David Johnson, Representative Kevin Koester, and Representative Art Staed *Facilitator: Cheryll Jones, Chair, Prevention of Disabilities Policy Council*

1:25 p.m.	**Concurrent Policy Development Workgroups**
	Workgroup 1: Building Inclusive, Accessible Communities that Foster Independence and Access to Healthcare *Facilitator: Louise Lex*
	Workgroup 2: Supporting Children and Families to Optimize Child Health and Development *Facilitator: Jane Schadle*
	Workgroup 3: Preventing Injuries that Result in Disability *Facilitator: Janan Wunsch*
3:15 p.m.	**Break**
3:30 p.m.	**Workgroup's Report Policy Recommendations and Audience Responds**
4:15 p.m.	**Closing Remarks and Next Steps** Cheryll Jones, Chair, Prevention of Disabilities Policy Council

Appendix B:
Information Resources

Information Resources

Building Inclusive, Accessible Communities that Foster Independence and Access to Healthcare

"*Building Inclusive, Accessible Communities that Foster Independence and Access to Healthcare*," Seekens, Thomas Ph.D., University of Montana, December 5, 2013.

"*More Than A Check-Up: Influencing Health & Development of our Children by Looking at the Big Picture,"* McWilliams, Jennifer, M.D., University of Iowa Hospitals and Clinics, December 5, 2013.

"*Use of Preventative Services by Children & Adults with IDD: Fiscal Years 2008 and 2009,"* Momany, Elizabeth; Damiano, Peter; Bacon, Robert; Lindgren, Scott and Riley, Ann, February 28, 2011.

"*The Health of Iowa Adults with Disabilities: 2008*," Ousmane, Diallo, M.D., 2008.

"*Providing Affordable & Accessible Health Care for Iowans with Disabilities: A Statement of Principles*," Report from the Prevention of Disabilities Policy Council's Forum on Access to Health Care for Iowans with Disabilities, December 2007.

Supporting Children and Families to Optimize Child Health and Development

"*More Than A Check-Up: Influencing Health & Development of our Children by Looking at the Big Picture,"* McWilliams, Jennifer, M.D., University of Iowa Hospitals and Clinics, December 5, 2013.

"*Adverse Childhood Experiences in Iowa: A New Way of Understanding Lifelong Health: Findings from the 2012 Behavioral Risk Factor Surveillance System*," Central Iowa ACE's Steering Committee, 2013.

Preventing Injuries that Result in Disability

"*Preventing Injuries that Result in Disability,"* Ramirez, Marizen Ph.D., University of Iowa, December 5, 2013.

"5 Leading Causes of Injury Deaths in Iowa," National Center for Injury Prevention and Control, Centers for Disease Control and Prevention, Data Source: National Center for Health Statistics (NCHS), National Vital Statistics System, 2011.

Lives and costs saved by motorcycle helmets, 2010. Washington (DC): National Highway Traffic Safety Administration, US Department of Transportation; 2012. Unpublished data

Vital Signs: Restraint Use and Motor Vehicle Occupant Death Rates Among Children Aged 0–12 Years — United States, 2002–2011. Erin K. Sauber-Schatz, PhD1, Bethany A. West, MPH1, Gwen Bergen, PhD Morbility and Mortality Weekly Report, Volume 63, February 4, 2014

"*Future Outcomes for Youth Sports*," Phillips, George, C., M.D., September 23, 2011.

"*Falls in Iowa – County Death Rates,"* Data from Iowa Department of Public Health, 2008-2012 averages.

Unintentional Fall Injuries

"*Falls in Iowa – A Policy Brief*," Iowa Department of Public Health, 2011.

"*Secondary Injuries Among Individuals with Disabilities*," Xiang, Huiyun, M.D., Center for Injury Research and Policy for the Research Institute at Nationwide Children's Hospital, 2012.